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ABSTRACT

To identify trends in state and local programs for retarded persons, the 51 state mental retardation coordinators were surveyed. Through telephone interviews information was obtained on the following topics: organization of state services, regional and local service patterns, the role of the private sector, budgetary trends, program trends, the impact of federal assistance, and the effects of recent legal rights developments. Among major findings were that 29 states, plus the District of Columbia, have made major realignments in state mental retardation services over the past 5 years; that almost all states were implementing some form of regional or county based service delivery system; that 20 respondents reported the area of community services as the fastest growing segment of their budget; and that 38 state coordinators ranked Medicaid and social services as the most important sources of federal revenue. (LS)

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Mental Retardation: Trends in State Services

U S DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

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Foreword

This volume is one of four that make up the Century of Decision series published by the President's Committee on Mental Retardation. Their common purpose is to chart the directions we must move during the next 25 years in order that America's retarded citizens may achieve a fuller life, and that fewer Americans shall be born or become mentally retarded.

State governments have been, are now, and increasingly will be a major factor in improving services for the development of retarded people, and in many cases preventing future retardation. As this report points out, State expenditures for day care and residential services alone exceeded $1.4 billion in 1972. That compared with $426 million spent by the U.S. Department of Health, Education, and Welfare, the major source of Federal funding.

It has been the policy of the Federal Government for several years, strongly reiterated by President Ford in his 1976 State of the Union message, to give "greater responsibility and freedom for the leaders of our State and local governments."

This decentralization toward the point where service is delivered should encourage tailoring programs toward the needs of the individual consumer, and making service-providers more accessible and more accountable to the consumer. These are major objectives of the President's Committee, as stated in "Mental Retardation: Century of Decision," the core volume of this series.

The present volume provides important background on the capacity of the States to participate in achieving these objectives. The President's Committee is greatly indebted to the National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR) and its Executive Director, Mr. Robert M. Gettings, for preparation of this report. We know of no other single source that covers the field so comprehensively.

It is PCMR's hope that State and local government officials will study and deliberate on the importance of their future planning and responsibility for mentally retarded citizens.

Fred J. Krause
Executive Director,
President's Committee
on Mental Retardation

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Chapter 1

Introduction

Tremendous changes have taken place in the field of mental retardation over the past two decades. New treatment techniques and methodologies have been introduced, hundreds of state and federal laws have been enacted, thousands of new community programs have been established and untold millions of public and private dollars have been expended to improve services to mentally retarded children and adults.

Despite the progress which has been achieved, our knowledge about emerging directions in programming for the retarded across the country is woefully lacking. Amazingly little nationwide data is available from which program trends can be extrapolated and implications drawn. We constantly hear pleas for narrowing the gap between scientific knowledge and clinical practice but few people seem concerned about the yawning gaps in our knowledge concerning service trends. And yet, every day decisions on the allocation of public resources are made by national and state policy-makers based on little more than the most rudimentary assumptions about what is actually happening in the field.

The purpose of this report is to identify a few of the developments currently underway in state and local programs for retarded persons and suggest some of the implications of these trends. Given the severe constraints on time and resources devoted to the collection of data and the preparation of the report, it would be both presumptious and foolhardy to pretend that this report does more than scratch the surface. However, if the report does nothing more than demonstrate the need for reliable methods of gathering systematic data on nationwide trends in serving mentally retarded persons, it will have served its purpose.

Methodology

During the Summer of 1974, the Association's staff was asked by representatives of the President's Committee on Mental Retardation for assistance in gathering information on patterns and trends in state services to mentally retarded children and adults. At the time, the Committee was in the final stages of developing a strategy for preparation of a major report to President Ford on mental retardation in the year 2000. PCMR members and staff recognized that information on current developments in state and local services would be a crucial ingredient in accurately projecting possible future events and, therefore, turned to the Association for help in gathering data on trends.

Because of the time constraints, financial and manpower limitations, and the dearth of nationwide data on state and local services to mentally retarded persons, it was agreed that a structured series of telephone interviews with designated state mental retardation coordinators would be the most rapid and cost-efficient means of gaining a sense of major nationwide trends. The Association's staff designed a survey instrument, modified it on the basis of a series of pilot interviews during the month of September, 1974, and proceeded to conduct the remainder of the survey interviews during October through January, 1975.

Approximately two weeks before each interview a letter was sent to the state coordinator explaining the purpose of the survey. The letter established a suggested time and date for the telephone interview and asked that the Association's staff be informed if this particular time proved inconvenient. A copy of the survey questions also accompanied the letter in order to give the respondent an opportunity to review them in advance of the interview.

Following each interview a letter was sent to the respondent thanking him or her for his or her participation. In addition, in instances where the respondent had promised to send specific materials or documents which would assist the staff in preparing the survey report, a reminder of this fact was included in the follow-up letter.

The decision to conduct a telephone survey was based on three factors. First, the Association had experienced a growing reluctance on the part of state coordinators to respond to mail questionnaires—especially to lengthy questionnaires which demanded considerable time and effort to complete. State officials are literally inundated with questionnaires and, as a result, often are non-responsive. Second, mail questionnaires, no matter how carefully designed, always are subject to misinterpretation which compromises the survey results. Telephone respondents, on the other hand, can be redirected by the interviewer if they have misinterpreted a particular question. Finally, many of the areas we were interested in exploring did not lend themselves to simple "yes or no" answers; instead, they involved gaining a sense of the respondents' views on the subject. We felt this objective could only be achieved through verbal interaction between the interviewer and interviewee.

The telephone interviews were conducted between September 1, 1974 and January 30, 1975. The elapsed time of the interviews ranged between 35 minutes and 2½ hours. Over 125 telephone calls were made by the staff (including attempts to schedule and reschedule interviews) and over 60 staff man-hours were expended in actual interviews.

We found the state coordinators highly cooperative and, indeed, eager to express their views on the developing trends in their states. It was apparent that many of them had gone to the trouble of verifying certain points with their colleagues in other agencies and/or had their staffs develop special information in response to certain questions. In addition, the Association received a wealth of follow-up materials for use in preparing the survey report. Without this spirit of cooperation, completion of this survey report simply would not have been possible.

This report is based on an analysis of the interview series. At several points, however, we have referred to other relevant published and unpublished information and data for purposes of comparison.

Our primary intent has been to identify the common themes which ran through our interviews with mental retardation program officials in the 50 states and, where possible, buttress these impressions with illustrations drawn from the interviews and the supportive documentation received from the states.

Limitations of the Survey

We would be remiss if we failed to alert the reader to some of the obvious limitations of this report and the survey upon which it is based.

First, since a majority of the information and data was gathered by telephone and has not been verified through other, independent sources, it is quite possible that recording and transmission errors have occurred. We have attempted to verify some information where published and unpublished literature was available; however, in a majority of instances there was no means of checking the accuracy of the reported data.

Second, as indicated above, many of the survey questions were highly subjective and, therefore, the interviewers were required to exercise considerable judgment in categorizing the responses. Given the complexity of the situation in many states, it was not surprising that conflicting indicators of trends were sometimes cited.

In such situation, the staff was forced to weigh the material presented and classify the responses as best it could.

Third, it was recognized from the outset that state coordinators, while often among the most knowledgeable observers of program developments in their states, were far from disinterested parties. In fact, during the initial negotiations with PCMR officials, the Association's staff recommended that a series of coordinated interviews be conducted with four or more key factors in each state (e.g., the state mental retardation coordinator, the state special education director, the state vocational rehabilitation director and a representative of a non-public advocacy group) in order to obtain a cross-section of viewpoints. However, due to time and resource limitations, this plan proved infeasible and, therefore, it was decided to limit the survey to state mental retardation coordinators.

Although most of the coordinators were quite open in their responses (and, indeed, frequently critical of the accomplishments of their own agencies), readers should recognize that they represent a point of view which is colored by their own experiences and an understandable commitment to the policies and programs which they have helped to shape. We suspect that it would not be difficult to find observers in most states who would disagree in some respect—and even disagree quite sharply—with the "state of affairs" as characterized by the state coordinator.

Fourth, state-to-state differences in the authority and responsibility of the state coordinator undoubtedly influenced the types of responses we received. Perceptions of how a large, complex service system operates differ depending on where one sits within (or outside) the system. The respondents varied from departmental commissioners to fourth and fifth rank officials in a complex agency structure. These differences must have influenced the survey results.

Finally, since many of the questions were quite subjective, there was no means of controlling interviewer biases. It would be foolish to suggest that the two staff members who conducted the interviews, both of whom are experienced in the field, came to the task devoid of preconceived notions about trends.

Although every effort was made to present the questions and record the responses in as objective and unbiased a manner as possible, it is probably unrealistic to expect that the opinions of the interviewers were not reflected in the translation and classification of the answers and, certainly, in the analysis and interpretation of the mass of verbal and written material received during the course of the survey.

In the same vein, since the interviews were conducted by two staff members, it seems likely that the same responses may have been treated and recorded quite differently. Unquestionably, such difference would have a significant impact on the final report.

The limitations listed above are, to say the least, formidable. Indeed, one might ask: was the time, effort and expense worth it? This is a matter which the reader will have to judge for himself. For our part, we will be satisfied if the study stimulates further discussions of ways to maintain a better sense of national trends in programming for the mentally retarded.

Organization of the Report

The report is divided into eight major sections. Chapter 2 reviews recent trends in the organization of state governments and comments on their implications for the delivery of services to the mentally retarded. Patterns in regional and local service systems are commented on in Chapter 3.

Chapter 4 focuses on the role of the private sector while Chapter 5 covers trends in public expenditures on mental retardation services, as viewed from the state level.

New and emerging developments in a variety of program areas are summarized in Chapter 6. The areas covered include education, vocational rehabilitation, residential services, community-based services, and health and preventive services.

The impact of federal assistance on state and local agencies and some of the problems it has engendered are analyzed in Chapter 7 while the implications of the strong emphasis on the legal rights of retarded citizens are covered in Chapter 8.

Robert Gettings,
Executive Director,
NACSPMR

Chapter 2

Organization of State Services

Since the initial impetus toward a coordinated nationwide attack on the problem of mental retardation in the mid-1950s, there has been a recognition of the central role which state governments must play in planning, delivering, coordinating and financing services on behalf of mentally retarded individuals. This recognition has been coupled with an awareness of the complex organizational problems involved in developing a comprehensive, integrated statewide delivery system which addresses itself, in a balanced fashion, to the varied service needs of mentally retarded children and adults with differing degrees and types of handicaps.

Because of the chronic nature of the condition and the wide-ranging needs of persons encompassed under the label of mental retardation, experts in the field long ago concluded that a variety of professional disciplines would be required to deliver the full range of health, social, educational, habilitation and rehabilitation services needed by retarded persons. For example, in 1958, a conference of leaders in the field, convened by the Council of State Governments, concluded that "the problems of the mentally retarded are not and cannot be the sole responsibility of any one department of State government." [1] The conferees went on to recommend: (1) that each department with a mandate to serve retarded persons have a division, bureau or special consultant "with specific responsibility for the development and administration of these services;" and (2) that each state establish an interdepartmental committee, council or board to plan and coordinate state services to mentally retarded persons. The President's Panel on Mental Retardation, in its 1962 report to President Kennedy, made similar recommendations.[2]

The attainment of the goal of active interagency involvement and coordination, however, has proven elusive in most states, probably due to a variety of factors deeply embedded in human and organizational behavior. As a result, administrative responsibility for mental retardation services is characterized by a striking degree of divergence from state to state, and there appears to be a continued groping for the "right" administrative solution in many states.[3]

Because of the unique problems posed by organizing and delivering state and local services to mentally retarded persons, the Association, in structuring the present survey, decided to devote major attention to this area. Our basic objective was to document current and emerging trends in the organization of state programs and obtain some sense of how they were likely to influence future developments in the field of mental retardation. With this in mind, we raised a series of questions designed to elicit information about the pace and direction of organizational changes, the impact of general administrative and organizational trends in state government and the attitudes of state program officials concerning these changes. The following is a summary of our major findings:

[1] "Report and Recommendations of the Conference on Mental Retardation," The Council of State Governments, 1958 (mimeo).

[2] *A Proposed Program for National Action to Combat Mental Retardation*, The President's Panel on Mental Retardation, U.S. Government Printing Office, October, 1962, pp. 165–67.

[3] For a detailed analysis of how the states are organized to deliver services to the mentally retarded, see *Organization of State Services for the Mentally Retarded: A Source Book*, National Association of Coordinators of State Programs for the Mentally Retarded, Inc., December, 1973.

Pace of Reorganization of State Governments

In speaking to state program directors across the country, the author was struck by the extraordinary pace of organizational change.

To a certain extent, the rapidity of change reflects the tremendous pressures placed on government at all levels—especially in the human services area—over the past two decades. It also mirrors the changing role of state governments within our federal system.

Despite the precipitous increase in federal expenditures since 1950, we often overlook the fact that outlays by state governments have been growing at an even faster rate. Indeed, between 1950 and 1972, the percentage of total governmental outlays expended by the Federal Government dropped from 60.3 percent to 52.5 percent. During the same period, the states' share of overall expenditures grew from 15.7 percent to 18.1 percent.[4] The bulk of these increased state expenditures have come in the areas of public welfare, education and related human services.

This rapid expansion of the role of state government was bound to induce some "growing pains." This, in turn, has led to efforts to streamline the structure through which state services are delivered. However, in the case of mental retardation services, the normal traumas of growth have been accompanied by a historical sense of uncertainty about the proper focal point for day and residential services within the structure of state government. This uncertainty has its roots in the evolving professional and societal attitudes toward mental retardation.

As Wolfensberger[5] and others have so graphically documented, during the early decades of this century the retarded individual was treated as either a sick, subhuman being, a menace to society, an object of pity or a combination of all three. These attitudes were clearly reflected in the services available—usually a few large, overcrowded and understaffed state-operated institutions. Usually these institutions either reported directly to the legislature or through a state welfare or health agency.

Later, with the emergence of mental illness as a major social concern in the late 1940s, mental retardation became identified as an extension of the mental health problem. Buoyed by the introduction of new psychotropic drugs and therapeutic intervention techniques, however, mental health agencies tended to pay little attention to the needs of mentally retarded persons during the 1950s.

It was not until the early 1960s that most states began to consider ways of giving clear organizational visibility to mental retardation services. Since that time we have witnessed a veritable flurry of reorganizations, most of which were designed to provide a stronger focal point for managing and coordinating day and residential services for mentally retarded persons.

The Association's recent survey revealed that of the 51 jurisdictions reporting, 43 states, plus the District of Columbia, had undergone at least one major reorganization of state mental retardation services over the past 15 years. A considerable number of states have gone through several major reorganizations since 1960. The fact that 29 states, plus D.C., have made major realignments in state mental retardation services over the past 5 years alone is an indication of the accelerating pace with which organizational changes are taking place.

[4] *Statistical Abstract of the United States, 1974*, 95th Edition, U.S. Department of Commerce, Bureau of the Census, U.S. Government Printing Office, 1974.

[5] Wolfensberger, Wolf, "The Origin and Nature of Our Institutional Models," *Changing Patterns in Residential Services for the Mentally Retarded*, Robert B. Kugel and Wolf Wolfensberger, editors, President's Committee on Mental Retardation, 1969, pp. 59–171.

State Organizational Trends

Consolidation of Administrative Authority

The establishment of discrete administrative units to plan, coordinate and manage statewide mental retardation service programs is one of the most pronounced trends which emerged from the Association's recent telephone survey. While the organizational position, functional responsibilities, authority, and staff resources of these agencies vary widely, taken together they reflect an emerging concern for mentally retarded children and adults within state government and, to a major extent, the growing political power of citizen groups which advocate on behalf of retarded citizens.

The Association identified 37 states which had created separate divisions, bureaus, offices, or departments of mental retardation, or had significantly strengthened existing units to administer day and residential services for retarded individuals, over the past 15 years.

There is, of course, no objective means of measuring the relative authority and effectiveness of any administrative agency; indeed, some may wish to quarrel with the way in which a few of the states have been classified in this study. However, even if several states were dropped or added to the "major organizational gains" list, it would not alter the basic conclusion that significant progress has been achieved over the past decade.

Establishment of Human Services Agencies

The formation of umbrella state human services agencies has been, by far, the most pronounced overall trend in the organization of state government.[6] The results of our survey indicate that 28 states, plus the District of Columbia, currently have umbrella human services agencies.

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[6] For further documentation of this trend, see Jensen, Allen C., "Dynamics of Change in State Government—Impact Upon the Developmentally Disabled," *Synergism for the Seventies: Proceedings of National Conference of State Planning and Advisory Councils on Services and Facilities for the Developmentlly Disabled*, Council for Exceptional Children, 1973; *Directory of State Human Services Agencies*, Human Services Institute for Children and Families, Inc., 1974; and Organization of State *Services for the Mentally Retarded: A Source Book*, ibid.

For purposes of this study, an umbrella agency has been defined as one which is administratively responsible for at least 6 of the following 11 federal-state programs: education of the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, comprehensive health, mental health, developmental disabilities and residential and community programs for mentally retarded persons.

Although the extent and direction of change is not yet clear in most states, the telephone survey revealed that the organization of state services for mentally retarded persons has been influenced by this trend toward the establishment of state human services agencies. One immediate yardstick of the degree of such influence is the fact that responsibility for day and residential services for retarded persons has been assigned to the umbrella agency in 22 of the 29 jurisdictions which currently have such an agency in operation.

Decentralization

The decentralization of responsibility for state human services activities is another pronounced, general trend which is influencing the direction of services to mentally retarded children and adults. Our survey found that 36 states had established or were in the process of establishing sub-state regions or service catchment areas. While the stage of development and the degree of authority and autonomy of these regions varied widely among states, the trend away from concentrating total authority in the state capitol seemed quite clear. The ramifications of this development for state mental retardation services will be discussed at greater length in the section of this paper dealing with regional and local service delivery systems. (See Chapter 3.)

Acceptance of the Developmental Disabilities Concept

Finally, there is an emerging trend toward broadening the legislative and administrative mandate of state mental retardation agencies to include services to other developmentally disabled persons. Since the enactment of the federal Developmental Disabilities Services and Facilities Construction Amendments (P.L. 91–517) in late 1970, our survey found that 13 states had changed the name of the agency responsible for day and residential services to encompass other developmental disabilities.

It is difficult to assess the current and long-range significance of this development. In a number of the states, for example, the name change has not been accompanied by a revision in the agency's basic legislative or administrative mandate. Indeed, the change appears to reflect, in part, preexisting practices (i.e., serving disabled clients with a primary diagnosis other than mental retardation) and, in part, a desire and willingness to expand services on behalf of non-retarded, developmentally disabled clients. In other states (e.g., California, South Dakota, and Wisconsin), however, there appears to be a real desire, supported by actions of the state legislature, to broaden the agency's mandate and adopt the ecumenical spirit and philosophy of P.L. 91–517.

Current State Organizational Patterns

The most striking impression in any examination of the organization of state mental retardation services across the country is the wide range and diversity of agencies involved. Given the variations in size, structure and organizational patterns, it is difficult to develop a taxonomy which accurately portrays the current picture.

The following generalizations can be drawn from an examination of available information:

Education. While the scope of authority varies considerably from state to state, basic responsibility for supporting and

coordinating the development of special education services on behalf of retarded children in the local public schools rests with a unit of the state department of education or public instruction (usually a division of special education). In general, responsibility for educating retarded youngsters in state institutions continues to reside in the agency of state government which operates such facilities; however, there is a trend toward transferring this authority to the state education agency (see discussion of this subject in Chapter 6).

Vocational Rehabilitation. State vocational rehabilitation agencies, although obviously differing in size, have basically the same operational missions, with two exceptions. Twenty-five states, plus the District of Columbia, have combined responsibility for the general vocational rehabilitation program and rehabilitation of blind individuals under the same agency. Twenty-five states still have separate agencies for general rehabilitation and rehabilitation of the blind.[7] Second, and perhaps more important from the standpoint of the mentally retarded, approximately 20 states operate state-funded, grant-in-aid programs for clients in long term sheltered employment (i.e., those who are too severely disabled to qualify for the federal-state vocational rehabilitation program).

Of the 50 general state vocational rehabilitation agencies, 20 are located in state education agencies, 16 in human services departments, 4 in welfare departments, 3 in labor departments, 4 under vocational education boards, and 4 under separate commissions or executive agencies. While inclusion of the vocational rehabilitation agency in the department of education remains the most common organizational pattern, the clear trend is toward placement of rehabilitation agencies in umbrella human services departments.

Welfare, Social Services, and Medicaid. The multiplicity of problems surrounding welfare families has led 46 states and the District of Columbia to consolidate responsibility for public assistance, social services and medical assistance programs under a single agency. In 28 of these jurisdictions, these functions are the responsibility of an umbrella human services agency. In the remaining 23 states, 19 have these functions combined under a welfare department, while in 4 states the welfare agency operates the public assistance and social services programs and the health department runs the medical assistance program.

Health and Mental Health. Responsibility for maternal and child health, crippled children, comprehensive health and mental health services also have been shifting toward human services agencies. Umbrella agencies are currently responsible for MCH services in 22 jurisdictions, crippled children's services in 25 jurisdictions, comprehensive health planning in 17 jurisdictions and mental health services in 25 jurisdictions. State health departments, which traditionally have been responsible for these functions, presently operate such programs in the following number of states: maternal and child health—27; crippled children—15; comprehensive health planning—15; and mental health—3 A total of 18 states currently maintain separate departments of mental health.

Day and Residential Services to Mentally Retarded Persons. The greatest amount of diversity is apparent in patterns of organizing day and residential services for mentally retarded persons. Despite recent reorganizations, responsibility for such functions rests with health, mental health, welfare, institutional management, mental retardation

[7] Figures furnished by the staff of the Council of State Administrators of Vocational Rehabilitation, Inc.

or consolidated agencies. Table 1 provides an overview of the types of state agencies involved. Even this typology, however, fails to capture all of the nuances in current organizational patterns. For example, over the past few years, the legislatures in six states have broadened the title of the mental health agency to include the words "mental retardation" or "developmental disabilities." These agencies are treated as "separate mental health departments" in this analysis.

Reactions to Current Organizational Structures

In an attempt to gain some sense of the relative effectiveness of existing state organizational structures, the interviewers asked each respondent for his or her opinion regarding the effectiveness and efficiency of the state's current system of delivering services to mentally retarded individuals. Given the fact that each of the respondents were key factors within the delivery system of his or her particular state and, thus, might be expected to have an institutional commitment or loyalty to the system, we hypothesized that most state coordinators would be supportive of the current organizational structure.

Table 1

Classification of State Agencies Responsible for Day and Residential Services

Type of Executive Agency	Community Services	Residential Service	States
Health	2	2	Hawaii, N.D.
Mental Health	14	14	Ala., Ind., Ill., Mass., Mich., Miss., Mo., N.Y., Ohio, R.I., Tenn., Tex., Va., W. Va.
Mental Retardation	2	2	S.C., Conn.
Umbrella Agency (Combined W/ Mental Health)	15	16	Alaska, Calif.,* D.C., Ga., Iowa,* Kan., Ky., Maine, Md., Nev., N.H., N.C., Ore., S.D., Vt., Wisc., Wyo.+
Umbrella Agency (Separate from Mental Health)	14	12	Ariz., Ark., Calif.,* Del., Fla., Idaho, Iowa,* La., Minn., N.J., Okla., Penn., Utah, Wash.
Institutions	4	5	Colo., Mont., Neb., N. Mex., Wyo.**

* Only public institutional services for retarded persons are under the mental health agency.
\+ Only community services for retarded persons are under the mental health agency.
** Only public institutional services.

Somewhat to our surprise, slightly more than half of the coordinators who expressed a view said they were dissatisfied with the present organization of services in their states. Twenty coordinators spoke positively about the present system. Twenty-one expressed negative views, while 10 either offered no opinion or voiced a mixed view.

The categorization of responses to this question is highly subjective and, therefore, prone to variation. The interesting point is the relatively high level of dissatisfaction with the present organizational structure among chief state program officials.

An examination of reasons underlying this sense of dissatisfaction is beyond the scope of this study. However, it seems reasonable to suspect that factors other than the objective features of the particular organizational structure are involved (e.g., the informal structure of the organization, the petty frustrations of bureaucratic life, and the inability to rationalize program philosophies with fiscal realities).

Since, as indicated above, the most dramatic general organizational trend affecting state services to mentally retarded persons is the establishment of state human services agencies, we decided to solicit comments from coordinators in states where such agencies are in operation. The response was mixed, with some coordinators emphasizing the advantages of umbrella agencies and others stressing the disadvantages.

By far the most frequently cited advantage (10 responses) was improved coordination with related divisions, bureaus and departments which are also part of the consolidated agency structure. For example, several state coordinators cited the fact that their states were able to take quick advantage of federal funding opportunities—such as Medicaid payments on behalf of state institutional residents or social services aid to community programs—because responsibility for both welfare programs and mental retardation services rested with the consolidated human services agency. With a single, high-level administrator responsible to the Governor for both programs, the petty bureaucratic jealousies and red tape were swept aside and differences in programmatic goals resolved in the interest of the fiscal well-being of the state and the betterment of conditions for its citizens.

Those who were unimpressed with the performance of human services agencies in their states cited the following reasons: (1) the tendency to create one or more new layers of bureaucracy, thus further obstructing the decision-making process (five responses); (2) the loss of identity for mental retardation in the huge, multi-purposed bureaucracy of the new umbrella agency (one response); (3) the lack of clear lines of responsibility (one response); (4) the confusion created by overlapping and conflicting rules established by various elements of the agency (one response); (5) the lack of a single point of accountability (one response); (6) the separation of line and staff decision-making (one response); and (7) the failure to properly delegate authority (two responses).

The greatest degree of dissatisfaction was expressed by respondents in states where central office staff had no direct control over the administration of state-operated facilities and programs for mentally retarded persons (i.e., day-to-day program responsibility had been delegated to regional offices, leaving the central office with policy-making and program coordination tasks). On the other hand, in those states where the consolidated agency functioned as a loose "holding company" for a number of relatively independent programs[8] state

[8] What the Human Services Institute's study refers to as an "integrated-coordinative agency." See *Directory of State Human Services Agencies*, Ibid., p. 3.

mental retardation officials generally seemed pleased with the arrangement.

Interagency Coordination

Perhaps more than in any other area of human services, the literature concerning the organization of mental retardation services stresses the crucial importance of coordinating and orchestrating a variety of services, delivered by a wide range of health, education and social service agencies. For this reason, we were interested in learning how many state coordinators rated interagency coordination in their state as relatively effective. Twenity-nine of the 48 coordinators who responded to this question felt that relationships between state agencies, on balance, were relatively productive. By contrast, 19 said they felt interagency coordination was rather ineffective in their states.

Those state coordinators who responded positively to the question cited the following reasons for the relative effectiveness of relationships between agencies in their states:

Table 2

Reasons Cited for Effectiveness of Interagency Coordination

Reason	No. of Mentions
Effective informal working relations with top level administrators in other agencies	17
Existence of an effective interagency coordinating committee council	10
Activities of the state developmental disabilities advisory council	7
Existence of a consolidated human services agency	3

General Organizational Trends

An effort was made to elicit comments from the respondents on broad organizational trends in state government which were having an impact on the delivery of services to mentally retarded persons. The answers of many state coordinators were not particularly responsive. Most of those who misinterpreted the question gave answers which alluded to programmatic trends in the field of mental retardation (such as deinstitutionalization and institutional reform).

Of those who offered relevant answers, the most frequently mentioned trends are summarized in the following table.

Table 3

General State Organizational Trends Affecting Services to Mentally Retarded Persons

Response	No. of Mentions
Establishment of a consolidated human services agency	11
Increased scope of gubernatorial authority	6
Formation of a strong state planning and budget office	6
None which have had a significant impact	6
Unresponsive answers	32

Given the wealth of documentation regarding such general organizational trends in state government as the expanding authority of governors and the growing power of state budget and planning offices, it was a little surprising to find that these phenomena apparently are not having a major effect in shaping mental retardation services—at least in the opinion of state program directors. Even those who offered what might be considered appropriate responses to the question did not leave the interviewers with the impression that these general organization trends are important forces affecting the delivery of services to retarded persons in their states.

General Administrative and Management Developments

In order to get some sense of the management techniques which were influencing the development and delivery of state services to mentally retarded individuals, a question on this subject was included in the interview. The statewide implementation of Management-By-Objective programs was the most

frequently mentioned development (16 responses). Also mentioned frequently were Program Planning Budgeting Systems (PPBS) and zero-based budgeting (9 responses).

On the whole, however, one got the impression that a majority of state coordinators viewed these new management and planning systems with a degree of suspicion. They tended to see them as activities of somewhat dubious value imposed on them by "management types," rather than as an important and integral part of their management armamentaria.

One interesting finding of the survey was the growing number of states which are attempting to implement client-based management information systems. Although the question was not raised explicitly, eight state coordinators indicated that their states were in the process of putting in place computerized client data systems which will give them tools upon which to base management decisions. The states included Arizona, California, Connecticut, Illinois, Louisiana, Rhode Island, Texas, and Vermont.

Chapter 3

Regional and Local Service Patterns

Twenty years ago an interested citizen could obtain a working knowledge of the service delivery system by studying the programs provided by two or three state agencies and the special services offered by local school districts and a handful of non-profit agencies—the latter generally under the sponsorship of a local association for retarded children. Today the situation is considerably more complicated. In addition to an expansion in the number and types of state agencies serving retarded clients and the growth in non-profit and proprietary service providers of all types, many states have attempted to decentralize responsibility for the management of community and some times institutional services to regional units of the state agency or to county governments.

Although the Association's staff recognized from the outset that it would be impossible, given the scope of the study, to examine all of the structural and operational implications of this trend toward decentralization, we did hope to document the extent to which states were adopting regional and county-based delivery systems and the stag of their implementation. Therefore, several questions regarding this topic were included in the interview schedule.

One of the most striking findings of the study was that practically all states were implementing some form of regional or county-based service delivery system. Although it was obvious that the system took a number of different forms and were in various stages of operation, 43 respondents reported that their states had developed or were developing a decentralized service delivery system. Of this number, 36 states were relying primarily on a regional system while 7 had opted for a county-based system. As a general rule, there appeared to be little reliance on municipal government as a means of delivering and coordinating the delivery of services to the retarded.

Since longitudinal data was not available, it is difficult to draw any generalizations about trends in local-regional delivery systems. However, the overall impression one received in speaking to state program directors was that the trend is toward defining multi-purpose (or special purpose) human service catchment areas rather than relying on existing units of general government (i.e., counties, cities and other municipalities). This inference can be drawn from the fact that a number of states which developed county-based systems 5 to 10 years ago (e.g., New York, Ohio, Pennsylvania, and Minnesota) are beginning to superimpose a regional structure on top of the county system. It is also evidenced by the fact that almost all of the states which have begun to decentralize service responsibility over the past four years have opted for a regional system (e.g., Alaska, Arizona, Arkansas, Florida, Louisiana, Mississippi, Missouri, Nevada, New Mexico, and South Carolina).

The reasons for this shift in the focus of responsibility are not clear. Three hypotheses, however, might be suggested. First, state officials may have learned that it is extremely difficult to maintain reasonable equity in the availability of services across the state given the sheer number of jurisdictions which must be dealt with (Texas, for example, has 254 counties) and the wide disparity in fiscal and human resources between counties and municipalities. Second, given the incidence of the problem of mental retardation—particularly the more severe forms of the condition which require extensive, specialized services—existing local jurisdictional lines, many of which were drawn in the days of the horse and buggy, provide inadequate service catchment areas. Cooperative arrangements between local jurisdictions often flounder on the rocks of local politics and inter-jurisdictional rivalries. Finally, the current pressures on many local governments—particularly urban jurisdictions—to provide basic municipal services such as fire and police protection, water and sewerage services, etc. are such that they are reluctant to assume new responsibilities.

Forms of Regionalization

Given the idiosyncratic features of the organizational structures of many states and the period of flux which currently exists, it is almost impossible to categorize regional service delivery systems. However, at the risk of oversimplification, we will try to suggest a few common patterns which appear to be emerging.

Discrete Regional Service Centers

We identified 10 states which are developing discrete, multi-service regional centers for those who are mentally retarded or developmentally disabled (Alabama, California, Connecticut, Idaho, Illinois, Kentucky, Missouri, North Dakota, Rhode Island, and Vermont). While the missions of these centers differ somewhat from state to state, they share the following common features: (1) A sufficiently broad catchment area (specially designated or shared with other human services programs) to make services easily accessible to the citizenry while still permitting the concentration of fiscal and professional resources to assure the efficient delivery of high quality services; (2) the provision of a comprehensive array of diagnostic evaluation, treatment, and training services —either directly or through the purchase of services; (3) a strong emphasis on alternatives to traditional institutionalization; (4) an interdisciplinary approach to the delivery of services; and (5) an exclusive focus on the needs of mentally retarded or developmentally disabled persons (except in the cases of Illinois, Kentucky, and Vermont where they also serve those who are mentally ill).

There are, however, many, often subtle, differences between the operational philosophies of states which rely on discrete multi-service centers. Among these differences are: (1) the operational auspices under which the program is run. In five states the centers are state-operated facilities (Alabama, Connecticut, Idaho, Illinois, and Missouri). In the remaining five states the centers are operated by non-profit agencies or specially formed boards under contract with the state; (2) some centers directly operate residential beds as part of their services (e.g., some of the regional centers in Alabama, Connecticut, and Illinois); others provide only non-residential services, although they often are responsible for pre-admission diagnostic and evaluation services, the purchase of appropriate residential services and may even control the admission and release of residents from state-operated institutions; and (3) as indicated above, the centers in some states concentrate exclusively on serving those who are mentally retarded or developmentally disabled, while in others they have dual responsibility for mental health-mental retardation services.

Designating Existing Institutions as Regional Service Centers

At least five states have elected to use one or more of their existing state institutions for the mentally retarded as the focus for a regional service system (Arizona, Florida, Louisiana, South Carolina, and Tennessee). They see two major advantages to this approach. First, the existing institutions have a concentration of professional and technical resources which could be duplicated only at great cost to the state. Second, by designating the institution as a regional center, the likelihood of breaking down the traditional communication barriers between the institutions and the community should be enhanced. Their hope is that they can significantly increase the degree of interaction between the central residential facility and community programs and, thus, create a true continuum of services for retarded citizens in the catchment area.

The types of residential institutions which are being designated as regional centers range from older, more traditional facilities to new programs which have been specially designed to facilitate interaction between residential and day-time programs. As might be expected, the resident population of these newer facilities tends to be considerably smaller than the older, traditional styled institutions. It is not yet clear what bearing this factor will have on the capacity of institutions to function successfully as regional service centers.

Regional Services Administrator/Coordinator

Depending on how they are counted, at least 12 states (Alaska, Georgia, Iowa, Maine, Massachusetts, Minnesota, Nebraska, New Jersey, New York, North Carolina, Ohio, and Pennsylvania) have appointed a regional/district or multi-county administrator to operate, coordinate and/or facilitate the development of community services within the catchment area. The scope of these officials' authority varies considerably from state to state. In a number of states they have little or no line responsibilities; rather they are charged with stimulating and coordinating local services (e.g., Alaska, Maine, and New York). In other states, they have specifically assigned responsibilities (e.g., in New Jersey, the field staff is responsible for guardianship, purchase of care, placement, day training, and adult activity services). In still other states, the regional service director has broad operational powers and a mandate to direct the activities of all community programs (and sometimes state institutions) within their catchment area. Among the states in the latter category are Georgia, Iowa, Nebraska, Pennsylvania, and Massachusetts.

The relationship of the regional services administrators to other human services programs varies from state to state. In some, the regional administrator has exclusive responsibility for mental retardation/developmental disabilities services and reports directly to the program administrator in the central office (Nebraska and New Jersey). In others, mental retardation and mental health services are combined at the regional and central office level and the regional administrator reports to the head of the central agency (Minnesota, Mississippi, New York, Ohio, and Pennsylvania). In still other states the regional M.R. administrator/coordinator (or the function itself) is part of the regional office of a state human services agency (e.g., Arkansas, Georgia, Iowa, and North Carolina). Depending on the organization of the state agency, the individual responsible for mental retardation/developmental

disabilities services in the regional office may report to his program counterpart in the central office or, through the regional administrator, to another element of the state agency.

Despite these differences, states with regional services administrators/coordinators have one thing in common: no direct services are provided to retarded clients through the regional office.

Regional Human Services Centers

At least one state (Delaware) is providing some direct services through regional human services centers. Two of the state's five existing human services centers provide-day training clinics for the mentally retarded. Several other states have experimented with such "one stop" service centers (e.g., Iowa and South Dakota).

The typology discussed above applies to most states with regional service systems; however, it does not capture all of the intricacies of how state-regional service delivery systems are organized. Some states fit two or more of the categories. For example, Texas could be said to have 3 parallel regional service systems, including 27 multi-county mental health-mental retardation centers, state-operated comprehensive developmental centers in 3 metropolitan areas, and outreach services provided by several of the state institutions in rural areas of the state. Some states have overlapping lines of regional authority. For example, all mental health and mental retardation services in Georgia are the responsibility of 14 multi-county health districts; however, the state legislature recently superimposed a system of 23 human resources districts and the responsibilities of these two systems are somewhat unclear. Finally, some states have both a county system and a regional system for delivering services (e.g., Iowa, New York, and Ohio). To determine the relative authority of the two systems, one would have to do an in-depth, state-by-state analysis—a task beyond the scope of the current study.

Authority of Regional Agencies/Administrators

It is difficult to determine the degree of authority and autonomy exercised by regional administrators in various states, although it is clear, even in this brief study, that there is considerable variation from state to state. In order to gain some tentative sense of the role of regional administrators/agencies and how well they were embedded in the state's system, several questions relating to the subject were raised in the course of the survey.

First, we attempted to learn when the state's regional structure was established. The answers we received can be categorized as follows:

- Seven states have had a regional system in operation for 10 years or more.
- Six states have had a regional system in operation for between 6 and 10 years.
- Six states have had an operational system for four to six years.
- Seven states' systems have been in operation for two to four years.
- Ten states have initiated regional systems within the past two years.

This data clearly illustrates the trend toward regional program in the states.

Second, we attempted to find out the number of states in which the authority and responsibility of the regional/local administrator/agency was established by statute. Of those responding to the question, 22 said that the authority and responsibility of the regions were set by the state legislature. Seventeen indicated that the regional/local agencies were created by administrative or executive action.

Finally, we tried to ascertain the number of states with county or regional agencies which have some type of revenue-raising authority. Eleven states indicated that county boards had authority to levy some type of real estate tax. Ten other states said that local and regional boards had no taxing authority but were permitted to solicit local jurisdictions for assistance from general revenues. Twenty-six states either failed to respond to the question or indicated that their local boards/regional offices had no revenue-raising authority.

Expansion of Regional/ Local Services

While it was not the purpose of this study to assess the effectiveness of community services, a number of states did cite examples to illustrate how rapidly community-based services for the mentally retarded have grown over the past few years. For example, the South Carolina Department of Mental Retardation furnished data which show that in a period of 8 years the state has moved from a position of having practically no community-based services to where, in 1975, there are 55 day care programs, 38 adult activities centers, 12 community homes and 60 family care homes across the state. In addition, during the upcoming fiscal year, the state plans to open 14 more day care programs, 10 adult activities centers, 25 community homes and 4 new summer training programs.

Many other states also cited examples of growth in community services. Maine, for instance, had a community services budget of $70,000 in 1970; this fiscal year the state will spend approximately $3 million (and local communities will obligate another $2 million in matching funds). Alabama expended only $25,000 on community services in 1969. This year the state is spending over $1.5 million. Practically every state official we spoke to had a similar success story to relate.

While increased expenditures and expansion of programs can not be the only criteria of success of regional/local programs, at least these data tend to underline the states' commitment to community service over the past few years.

Chapter 4

The Role of The Private Sector

Since the emergence of mental retardation as a major national concern in the early 1950s, the private sector has played an important role in providing services to retarded citzens and helping to shape public policy. Therefore, we were interested in learning how state mental retardation coordinators perceived the current role of the private sector in their states and what types of trends they saw emerging. Several questions pertaining to this area were raised during each interview.

For over 10 years the National Association for Retarded Citizens (formerly the National Association for Retarded Children) has urged its state and local affiliates to devote their major energies to convincing existing governmental and non-governmental agencies at all levels to furnish services to mentally retarded individuals, rather than the affiliates providing the services themselves. The Association's staff was interested in determining whether, in the opinion of the state coordinators, states and local ARC units had accepted this "obtain-not-provide" policy and allocated their resources and energies accordingly.

Twenty-two state coordinators said that the ARC groups in their states either had adopted or were moving toward the adoption of the role of a statewide advocacy group on behalf of the retarded. Thirteen reported that ARC units in their states were moving in the opposite direction—i.e., toward the primary role of a service agency. Seven state coordinators indicated that the associations in their states were continuing a long-established role of a provider agency.

We also were interested in discovering which organizations, if any, played key roles in the development of state policies—either through lobbying in the state legislature or through interaction with state administering agencies, or both. Of the coordinators responding to this question, 26 felt that ARC groups were an important force in shaping state policies, while 13 said the retarded citizen organizations in their states were largely ineffective in this area. Only a few state coordinators even mentioned other advocacy groups in their states, such as affiliates of the United Cerebral Palsy Association and the Epilepsy Foundation of America. Of those who did mention other organizations, four state coordinators said that state cerebral palsy units were playing a growing role and four reported that the UCP groups in their states had little or no influence. Only five respondents mentioned state epilepsy chapters. Two said these groups have a growing influence and three indicated they were relatively ineffective.

Eighteen state coordinators indicated that they could not detect a trend toward the uses of proprietary vendors of services in their states. On the other hand, seven state coordinators reported that there was a perceptible trend in this direction in their states (although two of the seven indicated that there was no major move in this direction).

These results may seem somewhat mystifying in view of the widespread reports of wholesale transfer of state institutional residents to proprietary nursing homes, intermediate care facilities, and other similar facilities. The discrepancy may be explained by the fact that the majority of proprietary facilities serving the retarded tend to be concentrated in a relatively small number of states and the practice of transferring residents in these states took place five or more years ago.

Although the question was not raised specifically in the interview, several state coordinators did express concern about the number of retarded individuals living in private boarding homes and various types of minimally supervised domiciliary care homes in their states. They voiced deep reservations about the quality of services provided such residents and the degree of state supervision.

Chapter 5

Budgetary Trends

One of the most effective means of assessing an agency's accomplishments is to examine its budget. The nature of this study did not permit us to review (or even inquire about) the budgets of the various state education, health, and social service agencies responsible for delivering services to the mentally retarded. We did, however, raise a number of questions concerning recent and projected budgetary trends in the area of day and residential services to mentally retarded persons, since this is generally the program area for which state coordinators are directly responsible.

As anticipated, the greatest number of states (20 respondents) reported that the area of community services has been the fastest growing segment of their budget over the past few years. However, 12 state coordinators indicated that institutional budgets have grown at a faster pace than any other program area. Four others said that the state's special education budget had grown more rapidly than either institutional or community services.

The responses to this particular question may have been influenced by the manner in which the question was asked by the interviewer. Thus, for example, several state coordinators pointed out that while the community services budget in their state had grown at a faster rate percentagewise, increases in real dollar outlays for institutional care were still considerably greater than for community services.

No comparative data on the cost of services to retarded persons were gathered during the course of the survey. Such an analysis was far beyond the scope of the study and, given the lack of standardized budgeting formats, impossible for the states to provide. Nonetheless, examples which illustrate expenditure trends in day and residential service porgrams were collected. Some are listed below:

- *Alabama* reported that the average per diem cost for a resident at Partlow State School and Hospital, the state's largest and oldest residential facility, increased from approximately $6.00 in 1967 to $30.00 last fiscal year. The total budget for the facility skyrocketed from $3 million in 1967 to between $15 and $16 million in 1974.
- In the decade from 1964 to 1974 the budget for the Mental Retardation-Developmental Disabilities Services in *Arkansas* (and its predecessor agencies) was increased from $1.04 million to close to $17 million—or almost a 1,700 percent increase. The state community service budget grew from $500,000 to $2.1 million between 1971 and 1974.
- Total expenditures by all state agencies in *California* for prevention of developmental disabilities and service to mentally retarded and other developmentally disabled persons is expected to top the $335 million mark in the current fiscal year—up over 20 percent from 2 years ago.
- The budget of the *Connecticut* Office of Mental Retardation has increased by 42 percent in the last 3 years.
- In *Louisiana* the number of state-operated residential facilities has grown from 2 in 1965 to 8 at present; during this same period, the budget of the Division of Mental Retardation has increased from $10 million to some $37 million.

- In the past 5 years, the budget for day training centers for *Georgia's* mentallly retarded citizens has grown from $50,000 to a phenomenal $24 million.
- *Idaho* has doubled its state budget for mental retardation services over the past 5 years (from approximately $3 million to $6 million).
- In 1969, *Nebraska* expended $600,000 to provide community services to 85 retarded clients. This year the state expects to spend $14 million in serving an estimated 3,000 clients.
- The budget of the *Ohio* Division of Mental Retardation and Developmental Disabilities was increased by over 400 percent between 1968 and 1975. In 1968, the Division served more clients in residential facilities than in community settings. Today, 4 to 5 times as many clients are served through community agencies as in state institutions, and the balance of the Division's budget has gradually shifted from 90 percent for institutions and 10 percent for community agencies to 70 percent for institutions and 30 percent for community agencies.
- In two years appropriations for the Family Resources Services program in *Pennsylvania* has grown from $800,000 to $4 million. During the same period the budget for the state's group homes programs has zoomed from $2 million to $13 million.
- The budget for the Ladd State School in *Rhode Island* has increased from $5 million in 1967 to $13 million in 1975, while during the same period the facility's total population has been cut from 1,200 to 840.
- The total budget of the *South Carolina* Department of Mental Retardation has grown from $9.5 million in 1969-70 to $26.8 in state funds and an additional $8 million in federal funds during the current fiscal year.
- The budget of the *South Dakota* Office of Developmental Disabilities has leaped from $60,000 in 1971 to over $1 million in the current fiscal year.

Certainly the above examples are not typical of budgetary trends in all programs in every state. But as we spoke to state program officials, we repeatedly heard similar illustrations of the growth in support for mental retardation programs. It is only human nature for a program administrator to take pride in his success stories and, perhaps in part, this explains the phenomena. However, the Association's staff came away from the series of interviews with the conviction that, despite discouragements and recurring obstacles, real progress has been made in the development and expansion of services to mentally retarded individuals over the past decade.

Chapter 6

Program Trends

During the course of each interview, an effort was made to determine how certain national trends were affecting programs within the particular state. The areas explored included education, rehabilitation, residential services, community-based services, and health and preventative services. The findings in each of these areas are summarized in this chapter.

Education

Forty-eight state coordinators reported that their states had mandatory special education laws on the statute books. Only two states (Mississippi and Ohio) indicated they had no existing statutory requirement that the public school provide services to at least educable and trainable mentally retarded children (or an equivalent category). These results closely parallel the recent findings of the Council for Exceptional Children.[1]

The rapidity with which state special education statutes are being updated and improved is indicated by the fact that 34 state officials reported that the mandatory special education statutes in their state had either been adopted or undergone major modifications in the past 2 years. This recognition of the public's responsibility for providing education services for all handicapped children constitutes one of the most promising programmatic trends in recent years.

Thirty-seven state coordinators reported that the mandatory special education laws in their states required the provision of services to all retarded children —regardless of the degree of their handicaps. Six states said that services are mandatory only for educable and trainable youngsters (including Georgia and New York, which exclude only the profoundly retarded). Respondents in the remaining states either didn't have mandatory statutes, failed to respond or were uncertain of the coverage authorized under current law. These findings are consistent with CEC results, which indicate that the mandatory laws of six states have exclusionary language relative to certain categories of mentally retarded children.[2]

[1] The Council for Exceptional Children, *Digest of State and Federal Laws: Education of Handicapped Children*, 3rd Edition.

[2] Ibid.

The interviewers also attempted to determine the eligibility age ranges for special education in the 50 states. The results of this inquiry are summarized in the following tables (Tables 4 and 5):

Table 4

Lower Age Limits for Special Education Services

Age Ranges	No. of States	States
No lower age restrictions	9	Iowa, Kansas, Massachusetts, Minnesota, Nevada, North Carolina, Oregon, South Dakota, Vermont
Ages 2 - 3	9	Alaska, Florida, Georgia, Illinois, Maryland, Rhode Island, Texas, Virginia, Wisconsin
Ages 4 - 5	14	Arizona, Colorado, Connecticut, Delaware, Hawaii, Maine, Michigan, Missouri, Montana, Nebraska, New Jersey, Oklahoma, Tennessee, West Virginia
Ages 6 - 7	13	Alabama, Arkansas, California, District of Columbia, Idaho, Indiana, New Hampshire, New Mexico, North Dakota, Pennsylvania, South Carolina, Washington, Wyoming
No response	6	Kentucky, Louisiana, Mississippi, New York, Ohio, Utah

Table 5

Upper Age Limits for Special Education Services

Age Ranges	No. of States	States
None	3	Alaska, Florida, Kentucky
Age 18	3	Indiana, Nebraska, Montana
Age 20	3	Hawaii, Maine, North Carolina
Age 21	32	Alabama, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Georgia, Idaho, Illinois, Iowa, Kansas, Louisiana, Maryland, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Vermont, Virginia, Washington, Wisconsin, Wyoming
Over 21	4	Massachusetts (25) Michigan (25) Minnesota (25) West Virginia (23)
No response or uncertain	6	District of Columbia, Mississippi, New York, Ohio, South Dakota, Utah

A modest but largely unsuccessful effort was made to document the direction of recent changes in state special education laws as they affect eligibility age ranges. Those who were in a position to offer a historical perspective, however, generally seemed to agree that the states had been widening the years of eligibility for special education services—both at the lower and upper ends of the scale.

Many state coordinators felt that they lacked sufficient knowledge to comment intelligently on the extent to which local public schools were attempting to "mainstream" retarded children, i.e., place retarded youngsters in regular classes with special, individualized assistance geared to their particular needs. Of those who did venture an opinion, 22 said that there were very few school districts in the state which were mainstreaming children. By contrast, 11 states indicated that mainstreaming was being used to some extent and 9 said it was being used to a considerable extent.

Several respondents expressed grave reservations about the inappropriate mainstreaming of children in their states—especially the wholesale placement of more severely handicapped youngsters in regular classrooms. A few even suggested that the mainstreaming "fad" had reached a peak in their states and, to quote one state mental retardation director, "the pendulum is beginning to swing back in the other direction."

Since most states have adopted statutory or administrative policies which provide that all handicapped children within a certain age range will be served by the public schools, we were interested in studying the extent to which these policies were being implemented across the country. Since state coordinators generally are directly responsible for providing services to severely and profoundly retarded and multi-handicapped youngsters in their state, we wanted to obtain their opinion on whether the public education system actually was carrying out its responsibilities to severely handicapped children. Thirty-five (35) state coordinators reported that it was the public school's responsibility in their state to serve severely and profoundly retarded children or see that such services were provided. However, of the 35 respondents, 22 said they could see scant progress toward programming for severely and profoundly retarded youngsters through the public schools. Ten said they had observed considerable (or at least reasonable) progress by the public schools in their state toward fulfillment of their obligations to severely handicapped children.

While the views expressed by state coordinators clearly are not unbiased by intrastate rivalries and institutional commitments, their judgment of the role being played by the public education system at least gives one reason to pause. Many of the changes in state special education laws have occurred so recently that it may be too early to assess whether they will have the desired impact. Indeed, it was evidenced in our interviews with state coordinators that laudable progress toward the goal of educating all children has been made in states such as California, Illinois, Minnesota, Pennsylvania, Texas and Washington. Nonetheless, an analysis of the history of state special education laws shows that there is sufficient grounds for prudent skepticism. Too often in the past, the gap between the promise of new legislation and the actual practice has been wide. Only time will tell whether the latest flurry of litigation and legislation will have its desired effect. Under the circumstances, if those who work with the most severely handicapped appear somewhat suspicious and doubtful, it is understandable.

Traditionally, the legal responsibility for educating handicapped children in state institutions has rested with the agency responsible for operating the institutions. Our survey reveals that this situation is changing as more and more states transfer this responsibility to the state education agency. Twenty state coordinators reported that responsibility for institutional education programs now rests with the state education agency. In 25 states, educating institutional residents is still the responsibility of the agency operating the facility. Six states either could not answer this question or did not respond.

Rehabilitation

Since the early 1960s, state vocational rehabilitation agencies have been involved in providing work-related evaluation and training service to mentally retarded clients. In 1973, Congress rewrote the former Vocational Rehabilitation Act, placing strong emphasis on services to severely handicapped clients. For this reason, we decided to ask state coordinators whether this change in the federal law had resulted in perceptible changes in the goals and activities of rehabilitation agencies in their states.

Only 15 of the 48 respondents indicated that there had been any noticeable changes in the activities of the state vocational rehabilitation agency as they relate to severely retarded individuals. Six others reported that strong cooperative relationships between the state vocational rehabilitation and mental retardation agencies had existed long before passage of the 1973 Act and this spirit of cooperation was continuing. The remaining 27 state coordinators who responded to the question said that they could perceive little or no change in the policies or priorities of the state vocational rehabilitation agency in their states. In some instances, they described past cooperative programs involving mentally retarded clients which had been worked out with the state rehabilitation agency; however, they indicated that there had been no new initiatives undertaken as a result of passage of the 1973 Act. Other coordinators stated quite bluntly that they had never received a great deal in the way of assistance from rehabilitation agencies and they did not see the situation changing. This impression is undergirded by the fact that over half of the respondents (22 out of 40) who gave a definitive answer said that mentally retarded persons were not being given a "fair shake" in gaining access to vocational rehabilitation services.

As we spoke to state mental retardation officials across the country, the Association's staff was struck by the wide variations in rehabilitation services delivered to the mentally retarded from state to state. It seemed clear that the responsiveness of rehabilitation agencies to the needs of mentally retarded persons—particularly those with severe handicaps—was more a function of the historical attitude of rehabilitation leaders in the state than any response to changes in federal law.

This impression is supported by statistical analyses of acceptance and closure rates prepared by the Rehabilitation Services Administration of HEW. In FY 1972, rates for acceptance of retarded clients varied from a high 20.7 percent in Missouri to 3.6 percent in West Virginia—or almost a six-fold difference. Variations among the states in the placement of severely handicapped clients was even more striking. As reported by state rehabilitation agencies on RSA Form 300, the percentage of completed cases of clients classified as moderately to severely retarded ranged from 0.5 percent in Kentucky to 5.8 percent in Indiana.

In fairness to state rehabilitation agencies, it must be said that, at the time of the survey, they had had precious little time to respond to the new federal initiative, since proposed regulations were not issued by HEW until June, 1974. In addition, Congress has placed vocational rehabilitation agencies in the difficult (some would say impossible) situation of improving services to the severely retarded while maintaining services to existing clients—all of this without any substantial increases in federal appropriations and during a period of serious inflation.

On the positive side of the ledger, state coordinators reported that the following cooperative vocational rehabilitation-mental retardation activities were now underway in their states:

- *California*—The state vocational rehabilitation agency has assigned counselors to the staff of each of the regional centers for the developmentally disabled in order to facilitate cooperative interaction.
- *Louisiana*—Fourteen evaluation and training centers for mentally retarded persons are currently in operation across the state, and the state vocational rehabilitation agency recently opened a sheltered workshop for severely and profoundly retarded clients.
- *Illinois*—A cooperative arrangement had been worked out between the Department of Mental Health and Developmental Disabilities and the Division of Vocational Rehabilitation whereby officials of the latter establish and monitor standards in workshops supported by the former.
- *Nebraska*—The Division of Rehabilitation Services has entered into contracts with each of the regional offices of the Office of Mental Retardation to furnish vocational counseling and work stations in industry for retarded clients. The Division of Rehabilitation Services has also aided in the large scale transfer of residents from Beatrice State School to alternative community settings.
- *New Jersey*—The Division of Mental Retardation and the Division of Vocational Rehabilitation have developed an arrangement whereby each client in a Division of Mental Retardation day training center is automatically referred to the state rehabilitation agency when he or she reaches age 16.
- *South Carolina*—The Vocational Rehabilitation Department is assisting the Department of Mental Retardation to locate suitable houses to serve as group homes for the retarded and also has begun to accept retarded workers, with minimal productive skills, into six or seven workshops across the state.
- *South Dakota*—Vocational rehabilitation has entered into cooperative agreements with every adjustment training center for mentally retarded persons in the state and has begun to move into community living programs.

These examples represent some of the better rehabilitation efforts currently underway across the country. Unfortunately, as indicated above, the record of achievement on behalf of more severely retarded persons is still rather spotty.

Residential Services

In the last few years, the national spotlight has been turned on the deplorable conditions in some of the most antiquated and under-financed residential facilities in the country. Hardly a week goes by that we do not read about a scandal or a lawsuit involving retarded residents in a state institution. And yet, despite all the wailing and gnashing of teeth, institutions are still with us and, in all likelihood, will continue to be for some years to come.

It is a bit ironic that amidst all the pleas for institutional reform, so few efforts have been made to document the changes actually taking place in public residential facilities.[3] Indeed, some of the scant national planning resources available have begun to dry up over the past few years.[4]

The present survey was not designed to gather "hard," comparative data on operating programs or to identify definitive statistical trends. Instead, we attempted to elicit the views of state officials who, in most instances, are directly responsible for administering state institutions, and, where possible, to collect some impressionistic data which would help to illustrate a few possible trends.

Service Goals

As expected, most states indicated that their highest priority goal was reduction in the size of the state's current institutionalized population (33 respondents). Six coordinators said the state's main goal is to improve conditions in existing institutions, while five states cited the need for a means of screening referrals and reducing the current waiting list. Six state directors reported that there is a need for additional residential beds in their state.

The responses from the remaining states were highly individualistic. Some cited the need for technological improvements (e.g., better intervention methods to work with disturbed retarded residents; improved implementation of the individualized planning process; and maximum stimulation and programming for severely and profoundly retarded residents). Others referred to required improvements in physical structures and staffing patterns (e.g., replacing old institutional buildings; increasing staff-client ratios; and phasing out the use of working residents). Still others mentioned more global goals (e.g., humanization of institutional care; move toward a regional service system; greater community orientation; and reorientation of the role of the residential facility).

Residential Population Trends

Thirty states reported that the average daily resident population in state-operated facilities had decreased over the past five years. Three states said their institutional population had increased while 10 indicated that the number of state institutional residents had remained relatively static.

In an effort to verify these reports and gain some sense of the magnitude of state-by-state population increases or decreases, we asked for an estimate of the then current resident

[3] The one exception is the recent survey report prepared for the President's Committee on Mental Retardation by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded. *Current Trends and Status of Public Residential Services for the Mentally Retarded: 1974*, NASPRFMR, 1975.

[4] Note, for example, the gradual demise of the patient movement data on public institutions, which was published on an annual basis by HEW until three years ago.

population and compared this figure with the statistics reported in the 1969-70 "Provisional Patient Movement" data for public institutions, as reported by HEW.[5] A total of 49 states and the District of Columbia provided us with useable estimates of their current institutional population. The results of our analysis can be found in Table 6.

Care must be exercised in using the statistics cited in Table 6. They are based on estimates provided over the telephone and have not been verified in writing. Thus, the figures are subject to errors in transmission and in the original estimates. However, for purposes of this brief overview, we were more interested in "order of magnitude" estimates than precise, verifiable data. The reader is warned to treat these statistics accordingly.

Even with this caveat, some rather interesting patterns emerge from the data in Table 6. The 50 jurisdictions can be divided into three basic categories: those which have reduced their institutional populations by 10 precent or more; those whose resident populations have remained relatively static (neither increased nor decreased by 10 percent or more); and those which have increased their institutional populations by 10 percent or more. Applying these criteria to the data in Table 6, 26 states fall in the first category (10 percent or greater decrease in population), 16 jurisdictions in the second category (static population) and 8 states in the third category (10 percent or greater increase in population).

As indicated in Table 6, the total number of residents in public institutions for the mentally retarded decreased by approximately 10. 2 percent between 1970 and 1973. This finding is roughly comparable to the information recently reported by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded.[6] The slight variance in findings of the two studies can be explained by the unscientific data collection methods and the differences in reporting periods.

There is a 134.5 percent spread between the state which experienced the sharpest percentage drop in resident population (Nebraska) and the state which displayed the largest increase (Georgia). Five of the 13 states which reported a 20 percent or greater reduction in their institutional population fall in the lower quartile of states in terms of total population (and 9 of the 13 states have a total population of 3.5 million or less). This finding suggests a possible relationship between the size and complexity of the state's institutional system and the relative magnitude of the problems found in reducing the number of residents in state-operated facilities. While no final conclusion should be drawn from these very preliminary data, experience seems to indicate that the states with the largest institutional populations face extraordinary problems in achieving successful deinstitutionalization. If this assumption is correct, it would be worth exploring the reasons for these difficulties so that strategies can be developed for overcoming them.

Geographically, 4 of the 13 states reporting a 10 percent or greater drop in their institutional populations are located in the Northwest or Rocky Mountain states. In fact, all 3 of the Pacific Northwest states have experienced a 20 percent or greater drop in population. By contrast, seven of the eight states with increased institutional populations are located in the South and Southwest.

[5] *Mental Retardation Source Book of the Department of Health, Education and Welfare*, Office of Mental Retardation Coordination, HEW 1972, pp. 19–20.

[6] *Current Trends and Status of Public Residential Services for the Mentally Retarded: 1974*, Ibid., p. 6.

Table 6

Population Trends in Public Residential Facilities for the Mentally Retarded: 1970–1975

		Resident Population as of		Total Increase/ Decrease	Percent Increase/ Decrease
		Jan. 1975	July 1970		
1.	Alabama	1,762	2,300	— 538	—23.4
2.	Alaska	110	109	+ 1	+ 0.9
3.	Arizona	1,050	971	+ 79	+ 8.1
4.	Arkansas	1,620	1,294	+ 326	+25.0
5.	California	10,000*	11,483	— 1,483	—12.9
6.	Colorado	1,700*	2,113	— 413	—19.5
7.	Connecticut	3,500	4,074	— 574	—14.0
8.	Delaware	575	568	+ 7	+ 1.2
9.	District of Columbia	1,364	1,242	+ 122	+ 9.8
10.	Florida	5,509	6,128	— 619	—10.1
11.	Georgia	3,568	1,864	+ 1,704	+91.4
12.	Hawaii	712	747	— 35	— 4.7
13.	Idaho	465	654	— 189	—28.9
14.	Illinois	6,800	7,877	— 1,077	—13.7
15.	Indiana	3,000	3,604	— 604	—16.7
16.	Iowa	1,460	1,623	— 163	—10.0
17.	Kansas	1,658	2,016	— 358	—17.7
18.	Kentucky	945	989	— 44	— 4.5
19.	Louisiana	3,800*	2,959	+ 841	+28.4
20.	Maine	586	799	— 213	—26.7
21.	Maryland	3,800	3,215	+ 585	+18.1
22.	Massachusetts	6,000	7,554	— 1,554	—20.5
23.	Michigan	7,100	11,834	— 4,734	—40.0
24.	Minnesota	3,600*	4,321	— 721	—16.7
25.	Mississippi	2,332	1,340	+ 992	+74.0
26.	Missouri	2,567	2,535	+ 32	+ 1.3
27.	Montana	550	944	— 394	—41.7
28.	Nebraska	1,000*	1,759	— 759	—43.1
29.	Nevada	NR	NR	...	...
30.	New Hampshire	740	970	— 230	—23.7
31.	New Jersey	7,500	6,846	+ 654	+ 9.5
32.	New Mexico	780	708	+ 72	+10.1
33.	New York	19,854	26,551	— 6,697	—25.0
34.	North Carolina	4,300	5,068	— 768	—15.1
35.	North Dakota	950	1,497	— 547	—36.5
36.	Ohio	8,000*	9,462	— 1,462	—15.4
37.	Oklahoma	2,100*	1,934	+ 166	+ 8.6
38.	Oregon	2,160	2,836	— 676	—23.8
39.	Pennsylvania	10,000*	10,621	— 621	— 5.8
40.	Rhode Island	839	851	— 12	— 1.4
41.	South Carolina	3,600	3,633	— 33	— 0.9
42.	South Dakota	1,180	1,197	— 17	— 1.4
43.	Tennessee	2,500*	2,785	— 285	—10.2
44.	Texas	13,200*	11,037	+ 2,163	+19.5
45.	Utah	850	863	— 13	— 1.5
46.	Vermont	466	628	— 162	—25.7
47.	Virginia	4,900*	3,661	+ 1,239	+33.8
48.	Washington	2,500*	3,738	— 1,238	—33.1
49.	West Virginia	500*	461	+ 39	+ 8.4
50.	Wisconsin	3,000*	3,781	— 781	—20.6
51.	Wyoming	600*	699	— 99	—14.1
	TOTALS	167,652	186,743	—19,091	—10.2

* Estimated NR Non-reporting

What are the reasons for these differences among states in the rate of reduction in residential populations? Certainly, no final answers emerged from our survey. One point, however, seemed clear from our conversations with state program directors: to equate success with depopulation is a gross oversimplification. Other factors must be taken into consideration, such as changes in the states' waiting lists for residential services. For example, South Carolina's resident population remained relatively stable between 1970 and 1975; however, during the same period, the number on the state's waiting list for residential services dropped sharply from 1,385 to 140.

Another factor which must be considered is the total number of facilities operated by the state. Most states have increased the number of state-operated facilities over the past 10 years while either decreasing the total number of clients in residence or maintaining a relatively stable resident population. A comparison of the facilities listed in the September, 1974 directory of NASPRFMR with the number reporting patient movement data in 1964 suggests that the total number of state-operated residential facilities has increased by over 80 percent in the past decade (from 135 to 246). Therefore, for example, one can only assess the 25 percent increase in the resident population in Arkansas against the background of a fivefold increase in the number of state-operated facilities (from one in 1964 to five in 1974).

A state with a mile-long waiting list and underdeveloped community resources will have a much more difficult time achieving a net reduction in its institutional population than a state with no waiting list and a history of relatively strong community programs. Or, to use another example, a state like New York which has a long history of operating residential treatment facilities, with thousands of long-term residents who would not be placed in an institution today, is in a much different position than, say, Arkansas, which only opened its first institution in 1957.

Of course, intangibles also must be considered, such as the program philosophy of the state's professional and political leadership and the economy of the state. Such considerations are impossible to measure but, nonetheless, important in assessing the deinstitutionalization efforts of a state.

The Role of Institutions

Our survey also revealed a major reorientation in the role of some existing public institutions. Although not all, or even most, older residential facilities have gone through this metamorphic process, it seems clear that more and more public institutions are adopting new roles which radically alter their functions in the array of services to mentally retarded persons.

Interestingly, three primary models of residential institution appear to be evolving. The first is most prevalent among newer residential service facilities. In most instances, such facilities are being designed and located to strike a balance between residential and community-based daytime services. Situated in urbanized areas, these centers view their residential component as just one among many services offered to the public. The regional centers in Connecticut and the new network of centers being constructed in the Chicago area would be two examples of this type of residential facility.

A second type of institution is the older residential facility which is being converted into a specialty facility within an integrated service delivery system. Such institutions admit only residents who cannot be handled in any other living alternative in the community. In addition, they attempt to place elsewhere residents whose needs no longer

coincide with the facilities' redefined service objectives. Often, admission to and release from this type of institution is controlled by a system outside the institution. The objective is to have the resident remain in the institution only long enough to reach predetermined developmental objectives, after which he or she is placed in an alternative community setting. California's institutions are a good example of this model.

The final type of institution is the older facility which is being converted into the hub of a regional or areawide service delivery system. Great emphasis generally is given to outreach activities and every effort is made to reorient the existing staff to create closer interaction and flow between the institution and community programs. A number of states are adopting this approach, including Florida, Louisiana, South Carolina, Tennessee, and Texas.

Our interviews suggest that state residential facilities, like all our social and political institutions, are evolving and changing to meet the needs of the times. The process of change may be too slow for many of us, and fraught with pitfalls and setbacks, but it is beginning to happen.

Characteristics of Resident Populations

In response to a question about changes in the characteristics of the resident populations of state institutions, almost all program officials (44 out of 48 respondents) agreed that the trend is toward a higher percentage of severely and profoundly retarded, multi-handicapped residents in state institutions. Other trends mentioned by a number of states included: (1) an increase in the average age of residents; (2) a growth in the number of residents with severe behavioral disorders; and (3) an increase in the number of residents with special needs (deaf-blind, cerebral palsy, communication disorders, etc.).

Community-based Services

Fastest Growing Program

Since many state coordinators reported that community services had been the fastest growing area of their state's budgets over the past few years, we were interested in establishing which types of community-based services appeared to be growing most rapidly.

The responses we received are summarized in Table 7.

Table 7

Fastest Growing Areas of Community Services

Service Category	No. of States*
Adult Activity	23
Day Training	21
Group Homes	11
Sheltered Workshops	13
Recreation	4
Preschool Programs	8
In Home Intervention	4
Other	9

* Some states listed more than one area.

Information and Referral

We also attempted to determine the information and referral resources upon which states rely to channel the retarded individual and his family to an appropriate service program. Of the states responding to this question, 11 said that the regional offices played the leading role in seeing that citizens received appropriate information about existing service programs and were referred to the right agency. Nine indicated that this function was performed by state institutions or regional service centers, while five states said that they relied heavily on associations for retarded citizens to direct parents to appropriate services. The remaining states indicated a variety of other information and referral resources in their states.

An apparently growing phenomenon in America is the use of "hotline" telephone numbers which citizens can use to learn about available human service programs. Five states said such telephone information systems were in operation in their states.

Effects of Mandatory Special Education

With more and more states maintaining special education services for all handicapped youngsters, we were interested in what effect, if any, this trend was having on existing day training programs for severely retarded youngsters outside the public schools. Three states said that day training programs were being reoriented to focus on preschool youngsters, 3 states indicated that the emphasis was being shifted to severely handicapped adults and 10 states reported that the programs of day training services were being restructured to deal with both severely disabled children and adults who were ineligible for special education because of their age. Responsibility for operating day training programs was being assumed by the public schools in four states. Eight states indicated that mandatory special education had not been implemented for severely and profoundly retarded youngsters and, therefore, the day training centers in their states remained unaffected.

Transportation

The lack of an appropriate, economical transportation system was seen as a major barrier to the provision of community services in 35 states. Indeed, many of the respondents in these states—without any prompting from the interviewers—indicated that transportation was the greatest impediment to program expansion in their states.

One was impressed by the wide range of approaches to the problem of transporting children and adults to and from daytime programs. Some have a separate category for transportation in the budget of community services agencies (e.g., Ohio and Rhode Island). Others (e.g., California and Nebraska) are resorting to reimbursing parents and others for transporting children to schools, workshops, etc. Still other states—particularly those with sparsely populated areas—are turning to five-day live-in centers for children who reside beyond reasonable commuting distance. All of these approaches have helped, but no state apparently has found the complete solution.

Health and Preventive Services

Twenty-two state coordinators felt that existing diagnostic and evaluation resources in their states were adequate, while 24 judged such services inadequate. A growing number of states are having considerable success with the use of mobile clinics or traveling diagnostic teams. For example, both Georgia and Louisiana use traveling diagnostic and evaluation teams in their statewide network of day training centers. New Mexico, which uses its institution-based traveling diagnostic and evaluation teams to extend services to rural sections of the state, has recently entered into a contract with the University of New Mexico to coordinate the teams' activities.

When asked about early case finding and intervention activities in their states, 10 state coordinators mentioned the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program under Medicaid. However, considering that every state has been required to have an EPSDT program since 1971, it is significant that more state coordinators did not mention the program as a casefinding resource. Indeed, a number of coordinators said that they had received few referrals for services from the program thus far.

One state (Kentucky) was in the process of having indigenous screening workers, using federal emergency employment funds, coordinate developmental screening as part of the EPSDT program. California was in the midst of implementing a 1973 law which requires that every child receive a comprehensive physical and mental assessment before entering the public schools.

The most frequently mentioned types of early intervention programs were preschool classes (nine responses) and infant stimulation projects (five responses). Many states either failed to provide any meaningful response to this question or said that their state had little in the way of early intervention programs. One state (Connecticut) had a series of pilot projects in operation—one in a depressed inner city neighborhood, one in a rural part of the state, and one in a medium-sized city.

Only a couple of states mentioned any prevention programs but both California and Pennsylvania were in the process of giving renewed emphasis to this important area. The California Advisory Council on Developmental Disabilities had sponsored a statewide conference on prevention and, later, $1 million was appropriated by the state legislature to implement a new prevention thrust. In a similar vein, $2 million had been allocated in Pennsylvania for prevention programs.

Chapter 7

Federal Assistance

Through the expenditure and obligation figures compiled annually by the U.S. Department of Health, Education, and Welfare, one can trace the rapid growth of HEW's commitment to assisting mentally retarded children and adults. In fiscal 1975, for example, the Department estimated that it would expend approximately $800 million on services to mentally retarded and other developmentally disabled persons.[1]

All of the state officials we spoke to during the course of the survey agreed that the Federal Government plays a much more important role in financing services to mentally retarded persons than it did 20 or even 10 years ago. However, despite this sharp increase in federal aid, the states continue to carry the lion's share of the fiscal load. A survey conducted by NACSPMR three years ago revealed that total state outlays for day and residential services alone (i.e., excluding all commitments for special education, vocational rehabilitation, maternal and child health, crippled children and other services) grew from approximately $375 million in 1963 to over $1.4 billion in 1972.[2]

We also attempted to gain some sense of which sources of federal aid were the most important in furnishing services in the various states. The criteria for determining relative importance was left to the respondent but interviewers stressed that the answer need not be in terms of total revenue received by the state. Thus, for example, several states gave high rank to programs which yield relatively less revenue to the state, because of the flexibility with which these dollars can be used.

Respondents were asked to indicate the three most important sources of federal assistance in descending order of importance. The results are summarized in Table 8.

[1] Testimony presented by HEW Secretary Caspar W. Weinberger before the House Subcommittee on Public Health and Environment on February 19, 1975.

[2] Testimony presented by Mr. David B. Ray, Jr., NACSPMR Legislative Chairman, before the House Appropriations Subcommittee on Labor–HEW, May 2, 1972.

Table 8

Most Important Sources of Federal Assistance to State and Local Programs Serving Mentally Retarded Persons *

Federal Program	Ranked by Number of States			
	First	Second	Third	Unranked
Social Services	22	9	4	15
Medicaid	17	12	6	15
SSI	0	5	6	40
Developmental Disabilities	2	6	11	31
Vocational Rehabilitation	2	3	4	41
Title I, Elementary and Secondary Education	3	9	12	27
Other	1	3	2	44

* A total of 46 states and the District of Columbia responded to this question; 2 states remarked on only 2 federal programs.

The vast majority of state coordinators agreed that, in recent years, welfare-related programs (Medicaid, social services, and public assistance) have become the most important sources of federal assistance to state and local mental retardation programs.

This view is certainly reflected in their rankings of the relative importance of various sources of federal aid. A total of 38 state coordinators ranked Medicaid (Title XIX) and social services (Titles IV A, VI and XX) as the most important sources of federal revenue. Indeed, 20 of these states ranked both Medicaid and social services as either the first or second most important sources of federal assistance.

State coordinators were also asked for their views on the major obstacles to obtaining and properly utilizing federal assistance. Fourteen states cited the lack of clear federal policies, while 12 others referred to the discontinuities in federal funding policies. Ten pointed to the uncertainties surrounding the annual appropriations process and one said that the mountain of federal "red tape" was a significant obstacle. Twelve coordinators indicated that most problems involving federal funding can be traced back to the responsible state agency, while 8 others pointed to the lack of consistency in policy interpretations among federal regional offices. The nine remaining answers did not fit into any of the above categories.

In general, it seemed clear that state program directors now spend a major portion of their time dealing with problems surrounding various federal programs. Throughout the interview series, we were impressed by the high level of frustration which is being generated by the interaction between Federal and State Governments. Apparently, this frustration level is growing at a rapid rate as the number and complexity of federal resources expand. Many coordinators indicated that they and their staffs seem unable to keep up with the ever-changing kaleidoscope of federal programs affecting mentally retarded persons.

Chapter 8

Legal Rights

Over the past few years, we have witnessed a virtual explosion of litigation and legislation aimed at assuring the legal and human rights of mentally retarded citizens. For this reason, in drafting the interview schedule, we included several questions on this subject. Our objective was to assess the overall impact of the recent flurry of lawsuits from the point of view of state mental retardation program directors.

When asked for an opinion on the most important developments in the area of legal rights of the retarded in their states, most coordinators cited recent court cases (9 responses), new state laws (12 responses), and changes in administrative policies (16 responses). The following were among the examples cited:

- *California* has established an administrative appeals process for residents in state institutions.
- The *Michigan* and *New York* legislatures recently adopted revised mental health codes which spell out the rights of mentally ill and mentally retarded clients and offer them additional due process safeguards. Similar "patient rights" legislation has been adopted in *Colorado, Florida, Indiana, Kentucky, Nevado, Ohio,* and *Virginia,* among other states.
- At least six additional states (*Alabama, Illinois, Nebraska, New Hampshire, South Carolina,* and *Vermont*) had legislative study groups working on revisions to the states' mental retardation codes at the time of the interviews.
- Three states have developed legal advocacy units for agency clients. Georgia, for example, has established a statewide advocacy unit within the Division of Mental Health and issued a booklet spelling out patient rights. The *Rhode Island* Division of Mental Retardation has contracted with the Rhode Island Legal Aid Society to provide a full-time attorney to represent clients, while the State of *New Jersey* has set up a cabinet-level advocacy office (with a section specializing in mental health and mental retardation).

During the course of the interviews, the Association's staff identified 19 states which have instituted new guardianship or protective services programs in recent years. Thirty states reported no recent changes in state guardianship laws or programs; however, in at least 3 of the latter states, efforts were underway to develop new guardianship statutes.

A total of 13 state coordinators felt that the protective services/guardianship system was meeting the needs of retarded citizens in their states. Twenty-four respondents said the current system was not functioning well and needed to be changed. Significantly, 10 of the 19 states which have recently instituted new guardianship plans rated their current system "adequate" while 4 others said it was too early to judge.

Appendix A

Interview Schedule

Organization and Delivery of Services

State Services

What significant changes have been made in the organization of state government over the past 15 years that have affected the delivery of services to mentally retarded persons? Briefly describe these changes.

In your judgment, to what extent does the current organizational structure in your state enhance or impede the efficient and effective delivery of services to mentally retarded persons?

What impact have general organizational trends in state government had on the delivery of public services to retarded persons in recent years (increased gubernatorial authority, formation of strong planning and budget agencies, establishment of umbrella departments)?

The report of the President's Panel on Mental Retardation, issued in 1962, placed heavy emphasis on the need to effectively coordinate the activities of various state agencies engaged in delivering services to mentally retarded persons. What formal or informal mechanism exists in your state to affect such interagency coordination of services? In your judgement, how effective have these efforts been in achieving the goal of an integrated, client centered system of services? Does the state Developmental Disabilities Council successfully perform this function, in your opinion?

What other administrative or management developments, if any, in your state (PPBS, Management by Objective, etc.) have had a significant impact on the ways in which services are delivered to retarded persons?

Local and Regional Delivery of Services

What steps have been taken over the past fifteen years to establish a regional or county based system for administering, coordinating, and/or delivering community based services to mentally retarded persons? When was this system initially established? How effectively is it functioning?

What type of legal authority does this local board, center or administrator exercise (levying taxes, distributing state grants-in-aid, operating direct service programs, monitoring program standards, etc.)?

Role of the Private Sector

Has the role played by consumer interest groups in delivering and promoting the development of services for retarded persons changed significantly over the past decade? If so, please explain.

Do you feel that the role of the private sector (non-profit and proprietary) as vendors of direct services to the retarded population in your state will expand or contract in future years? What trends are presently observable? What are the implications of these trends for state agencies interested in retarded persons?

Budgetary Trends

What significant trends are observable in the allocation of the state's resources for mental retardation programs over the past decade (i.e., what programs have fared best in the "battle of the budget")?

Program Trends

Education

Has your state adopted a mandatory special education statute (year of adoption and year of full implementation)? What impact has this statute had on the expansion of educational services to retarded youngsters?

To what extent are school systems within your state "mainstreaming" retarded youngsters —i.e., placing former or potential special class students back into regular classroom settings?

To what extent are local school districts in your state assuming direct responsibility for educating severely and/or profoundly retarded children? To what extent are they assuming similar responsibilities for institutionalized children and children who

traditionally have been educated in non-public school settings?

Rehabilitation

The Rehabilitation Act of 1973 directs state vocational rehabilitation agencies to give priority to serving more severely handicapped clients. What impact has this statutory mandate had on the vocational rehabilitation program in your state as it affects services to retarded clients?

To what extent have cooperative agreements between the state vocational rehabilitation agency and other state agencies (education, institutions, etc.) played a role in expanding job opportunities for retarded workers?

Do you find that employment opportunities are expanding for retarded workers in your state?

Residential Services

Over the past few years has the average resident population in public institutions for mentally retarded persons been increasing, decreasing or remaining steady? What have been the major contributing factors to these population trends (e.g., aggressive placement programs, stiffer admissions criteria, greater family and community acceptance of retarded persons in the home, reduced or increased incidence, etc.)?

What types of alternative residential programs are available within your state? Under whose auspices are such programs operated and how are they funded?

Briefly outline the activities and plans your state has for: (1) reducing the population of state-operated residential facilities; and/or (2) improving conditions within existing facilities.

In what ways have the characteristics of the resident populations of state-run facilities for mentally retarded persons changed over the past twenty years (degree and nature of handicaps, age distribution, etc.)? In your view, what implications do these trends have for the future of residential programming for retarded persons in your state?

To what extent has your state utilized Title XIX (Medicaid) funds on behalf of institutionalized residents in public facilities? If not, is your state planning to qualify for such aid in the near future? If Title XIX funds are being received, to what extent have these funds been used to improve services on behalf of institutional residents?

What steps has your state taken to comply with proposed Labor Department regulations governing the payment of working institutional residents? What problems, if any, are these new rules causing you?

Community-Based Services

What types of community programs appear to be developing most rapidly in your state (comprehensive, multi-service centers, day training, adult activity, recreation, pre-school intervention programs, etc.)?

What types of information and referral services exist in your state? How effectively are parents being channeled to appropriate service programs?

What impact, if any, has mandatory special education had on the operation of daytime programs for severely handicapped children in your state? What changes or adaptation, if any, are you seeing, or do you expect to see, in the operating goals of such programs?

To what extent does the lack of available transportation services (both general and specialized) hinder the development of community services in your state? What, if anything, is being done to eliminate current transportation barriers?

Health and Preventive Services

Have the diagnostic and evaluation resources of your state increased appreciably over the past 10 years? In your opinion, are there adequate D & E clinics available in your state at the present time to handle the population?

What types of early identification and intervention efforts are currently underway within your state? Are these efforts adequate? If not, what plans, if any, are being made to expand them?

Federal Assistance

What sources of federal aid comprise the three most important avenues of federal assistance on behalf of retarded persons in your state?

In your opinion, what are the most significant obstacles to obtaining and properly utilizing federal funds to meet the needs of mentally retarded persons in your state (e.g., lack of continuity in Congressional and federal agency objectives, uncertainties over annual appropriations, federal "red tape", lack of clear policies on expenditure of generic service funds for retarded persons, etc.)?

Legal Rights

Do you feel that the general society, and service agencies in particular, have become more sensitive to the rights of mentally retarded persons over the past few years? If so, to what factors do you attribute these changes (the visibility of court suits, an increased sense of militancy among parent and other advocacy groups, etc.)?

What specific legislative and administrative steps have been taken in your state in recent years to safeguard the individual rights of mentally retarded citizens?

Has your state instituted a new system for providing guardianship and protective services to mentally retarded individuals in recent years? If so, indicate how the system functions. If not, are efforts underway to develop such a system?

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